User Participatory Methods for Inclusive Design and Research in Autism: A Case Study in Teaching UX Design

Abstract. User participatory design is considered to be one of the best methods for understanding the needs of a target audience and creating high quality, well designed solutions to meet their needs. For many design students, the principles of participatory design in the creation of new user experiences are part of their curriculum. However, the involvement of disabled persons into the user experience design (UXD) process can be difficult in an educational setting. Often persons with autism and cognitive disabilities are excluded from user experience data collection due to their lack of sufficient cognitive ability and language skills to participate in these research methods in meaningful ways. Further, educators may shy away from involving this group due to institutional regulations and ethical concerns. This paper presents a case study introducing design students to inclusive UXD strategies and observing autistic children, using an approach called the "Connectivity Model". The model avoids the requirement for complex ethical clearance by facilitating observations via recorded videos. We present outcomes and evaluate the model against the most pertinent needs of these children.

Keywords: Participatory design, Autism, Design education, Higher education, User experience design, Serious games

1 Introduction

Working with actual target audience groups in university design courses is often difficult because of the time involved in creating user experience design (UXD) research protocols and gaining approval to conduct the study with actual users. Further, disabled persons are protected from certain types of user research in the United States and other countries thus making their participation in UXD research even more difficult. However, there is great value in considering the needs of this user group as there can be particular design challenges, and outcomes can be revealing and rewarding. In order to include these user groups in testing or observations, the research methodology must go through intense scrutiny to ensure their rights as a protected population as indicated by the relevant Institutional Review Board (IRB) or Ethical Approval process. In addition, children under the age of 18 are not able to give consent and an assent process must be used along with the typical consent forms given to the parent or guardian.

Because of this complicated and potentially lengthy review process, including these audiences in the research process for students in a UXD course is difficult. However, without meaningful input from these persons in the design process – amongst the input from other stakeholders – the resulting products and services may not adequately meet their specific needs and preferences. Further, it is highly beneficial to students

to learn together in an environment that closely resembles the real-life equivalent, which in this case is conducting research with autistic people. Such situated learning aids students' progress by creating a community of practice (Lave and Wenger 1990). Therefore, we consider it highly beneficial to teach design students how to be IRB compliant in their research and at the same time use methods that consider input of the autistic target audience in ways that are sensitive to their needs, do not violate their human rights, and allow participation in appropriate and meaningful ways. This paper will present and evaluate such a model of participatory UXD for autism that can be incorporated into university design courses.

1.1 A case for early intervention

The US Center for Disease Control (CDC 2012) found that one in 68 children aged 8 years old have an autism spectrum disorder (ASD). While no intervention has yet been shown to reduce the prevalence of ASD, the CDC recommends that early support and intervention might maximize the ability of children to function and participate in their community. In addition, initiation of school-based services prior to formal school entry might aid educational progress. Chez (2008) noted that autism does not typically shorten the lifespan, therefore society needs to prepare for long-term support of these children as they grow to adulthood. We argue that improving early intervention and quality of life, improving social impairments in communication and awareness of others, and potentially reversing some aspects of these autistic behaviors at a neurological level will benefit everyone.

1.2 Identifying key challenges

Satterfield et al (2012) found that parents and teachers of children on the autism spectrum were in strong agreement when identifying the most difficult social, communication and behavioral issues facing these children. Both participant groups were asked to complete an online survey and rate the importance of the children's social skills (6 questions), communication skills (7 questions), and behavioral skills (7 questions) when performing their roles in taking care of the children, on a 1-5 Likert scale. The most important skills (average ranked 4.5 or higher by both parents and teachers) identified were:

1. The ability to avoid or control "tantrums", "melt downs" or "acting out."
2. The ability to understand that other people have feelings.
3. The ability to understand social situations.
4. The ability to understand the thoughts, words, and communication of other people.
5. The ability to use age appropriate speech and/or language for communication.

In a large-scale qualitative study, Wittemeyer et al (2011) found that enabling autistic persons to have control and make their own choices is a key factor in reaching a "good outcome" for their adult life. With regards to parents' aspirations for their autistic children, the top priorities were:

1. emotional wellbeing (25%),
2. the ability to build social relationships (25%),
3. employment (22%), and
4. developing independent living skills (19%).

Generally, any intervention that aims to support autistic children and prepare them for adult life ought to therefore focus on abovementioned key challenges.

1.3 Participatory design

Human-centered design approaches have long advocated for the active involvement of users in the design process in order to gain a clear understanding of user and task requirements (Maguire, 2001). This may be in the form of interviews, focus group, prototype testing and final system evaluation. Participatory design takes this further by considering the user not simply as a source of information or evaluator of the final product, but as an active contributor of design ideas and a decision-maker in the design process (Sanders and Stappers, 2008). There is a growing body of research concerned with involving people on the autism spectrum in the design of products targeted at this group.

Much of the participatory design literature in this field focuses on adequately representing the needs and requirements of children (Börjesson et al 2014), people with learning difficulties or communication impairments, teenager and young people (Fabri and Andrews 2016), or those with difficulties imagining how they themselves or others might use the product (c.f. Millen et al., 2010; Coons and Watson, 2013). Children can be informants or design partners in the process (Druin 2001), with parents and teachers often acting as proxies, experts or facilitators (Börjesson et al 2014). There is a clear need for UX designers to understand how to follow a participatory design process that is both sensitive to the characteristics of the user group and evidence-based.

1.4 Training the next generation of designers

Universities have a duty to prepare future UX designers in the best possible way for the challenges of design practice – especially where the end product needs to be highly inclusive and accessible. The importance and feasibility of a practice-based approach has been shown before (Fabri 2015; Lugmayr et al 2011). Going through the participatory design process with disabled or neuro-diverse users presents particular challenges as it requires students to be open to the needs, limitations and preferences of this group. Commonly held assumptions about users may not be valid (cf. Fabri and Andrews 2016), and UXD students need to learn how to involve autistic target audiences in meaningful and ethical ways. In order to do this, the design students need to have a firm understanding of how to conduct such research.

In this paper, we will investigate how the Connectivity Model, a participatory design research method developed by Kang and Satterfield (2009), can be used in a university context. We will embed the method into the UXD teaching curriculum of a university design course for senior students. In particular, we will explore the effectiveness

of specific research tools in helping students identify the needs of an autistic target audience. We also demonstrate a method of using the Connectivity Model UXD data collection tools with a carefully selected series of videos on a YouTube channel of ASD and classroom situations as an alternative to in-person ethnographic observations. This gives the advantage of eliminating a need for a complicated IRB and access to a classroom with the appropriate student population for this type of observation. This greatly increases the ability to teach UXD for ASD in a university setting that might otherwise lack such access for students to observe ASD.

2 The Connectivity Model

The connectivity model is a UX research method that collects data in social, emotional, behavioral and motivational areas. It was developed for the inclusion of persons with cognitive disabilities and autism into the user experience design cycle as part of a participatory design process (Kang and Satterfield 2009). The model analyzes user data based on socially and emotionally appropriate practices in relation to the community of the target audience. It further considers physical constraints such as ability in the areas of physical, cognitive, and developmental areas and combines this into the optimal design zone.

This design zone takes into consideration not only what a particular person or group can do, but also what they prefer or desire to do in their daily lives. The model encourages the designer to develop deep empathy for the end user before starting the creative design process. In this respect, it is not unlike the early stages of Design Thinking approaches (cf. IDEO 2015) which advocate a deep inquiry into a user's motivations, abilities, concerns, dislikes and personal preferences. The Connectivity Model combines methods from Kansei Engineering (Nagamachi 1999) and Activity Theory (Engeström 1993) and incorporates audience analysis in the areas of physical and cognitive abilities and primary motivating factors. *Kansei Engineering* is an evaluation methodology that focuses on how people respond emotionally to products, packages, and brand experiences. It addresses the question of why people like a product, package, or brand in terms of its sensory and tactile properties. Activity Theory (AT) was developed by Russian psychologist Lev Semenovish Vygotsky. It provides a framework for evaluating how social, cultural, and historical conditions influence people. The Connectivity Model applies the combined metrics into a cohesive method of analysis and to the design of artifacts, environments and experiences for persons from all ability levels.

Connectivity Model UX Worksheet

Positive Social Issues	Negative Social Issues
Positive Emotional Issues	Negative Emotional Issues
Positive Behavioral Issues	Negative Behavioral Issues
Physical Conditions	Motivational Issues

Figure 1. The Connectivity Model Data Collection Worksheet.

3 The Play•IT Design Project

Play•IT is the title of a pilot study assignment in a university design course for senior students. It was offered as a way to investigate the design of UXD data tools and their use by students as a way to collect and analyze UXD data for use in studio projects. Here, it acts as the case study for evaluating a participatory design method.

The objective of the Play•IT project is to design an educational game that mediates social interactions between typical children and children on the autism spectrum. The emphasis is on creating a designed solution that addresses the social, communication and behavior skills needed by children with autism as they interact and play with their neurologically typical peers on an equal basis.

Play•IT was taught in Fall 2016 as part of an online course, DESN 482: Research Methods for Inclusive UX Design at California State University Long Beach. The class focuses on research methods, design for social inclusion, and design for behavioral change. DESN 482 is an upper division, fully online course in a 4-year design major. The online format was chosen because it offers many options to students in the areas of content delivery, access to digital information and a minimized bias in the classroom with regard to race and gender (Satterfield and Kelle, 2016).

The course uses inclusive UXD tools and strategies to identify differences in social, ethical, and physical abilities in multiple target audiences. It also takes into consideration the importance of age appropriateness and stylistic appeal to both the child with disabilities and to the typical peers (cf. Satterfield, 2010).

3.1 Project requirements

The solutions students create for the Play•IT project had to meet the following requirements:

1. It had a primary target audience of children ages of 6 and 12 years old;
2. Accommodate the social, ethical, and physical issues face by all constituent groups including peers, teachers, and parents;
3. The project solution must be age appropriate and interesting to both the child with autism and to their neurologically typical peers;
4. It must not be designed or branded as an "autism" or "disabilities" product;
5. It must have learning outcomes that are beneficial to both constituent groups.

Students were expected to design and prototype all interfaces, objects, spaces and other essential elements to demonstrate the functionality of their final solution. The project goals were:

1. Incorporate multi-sensory data into a UXD solution;
2. Incorporate information design for multiple audiences;
3. Create a visually dynamic solution that appeals to multiple audiences; and
4. Incorporate a fun UXD solution with social, emotional and behavioral learning experiences.

3.2 Course Structure

Lectures. Ethnographic information was given through a series of lectures on autism, the Connectivity Model, audience analysis, motivation, behavior modification techniques, and branding. Students were also required to complete the IRB training for social and behavioral research (cf. Satterfield, 2016). Guest lectures with parents of children with autism were included into the online weekly meetings. The students were required to write out questions for the parents prior to their guest presentations and then submit the completed questions and answers based on the information from the presentation.

Data gathering. Students were asked to collect ethnographic data by observing and analyzing pre-selected YouTube videos from a variety of natural and school settings, complemented by insights from a literature review. Using a worksheet based on the Connectivity Model (Fig. 1), students recorded the autistic and typical child behaviors they observed. This was done by using a YouTube channel with videos edited for the purpose of allowing students to observe and record both typical and ASD children. The data from these ethnographic observations was then used to inform the final Play•IT design solutions by connecting the UXD research findings and letting this inform user personas, journey maps, and design solutions for the final project.

Assessment. Class assessment was done via weekly assignments posted to an online course management tool. Students were required to login once a week for live lectures, project evaluation, and group critiques. Students participated in additional ac-

tive learning or constructed learning experiences such as making a video of themselves demonstrating a favorite toy and discussing why it was fun or educational. They also posted discussions of favorite online games for children. Students were required to complete and document the following aspects of their research and design:

1. Identify and research multiple target audiences,
2. Develop a series of user personas;
3. Complete the IRB test and generate interview questions for a parent
4. Conduct ethnographic observations with the Connectivity Model worksheet;
5. Create a design with sketches, and low, mid and high fidelity prototypes; and
6. Demonstrate the game play and educational content.

4 Results

The final projects were constructed as high fidelity prototypes. Students were encouraged to choose a method of final construction that best demonstrates their concept and thoroughly document it through photos or digital images. A process book was created to document their UXD research including user personas, compilation of research questions and interview data, ethnographic observations and data interpretation.

4.1 Student Project 1: Perry Penguin

Perry Penguin (Fig. 2) is a multi-sensory game designed using the Connectivity Model to incorporate textures, colors, and sounds into a fun, learning environment. A snowball is used to bowl over the penguins and to identify the related colors and two-term concepts.

Figure 2. Perry Penguin game solution for Play•IT

4.2 Student Project 2: Tumi Turtle

Tumi Turtle (Fig. 3) is a tabletop game interface that allows children to play both individually or in groups. The turtle has a screen on the top and a projector that displays onto a wall for groups to interact. Color, sound and interactivity are incorporated into table.

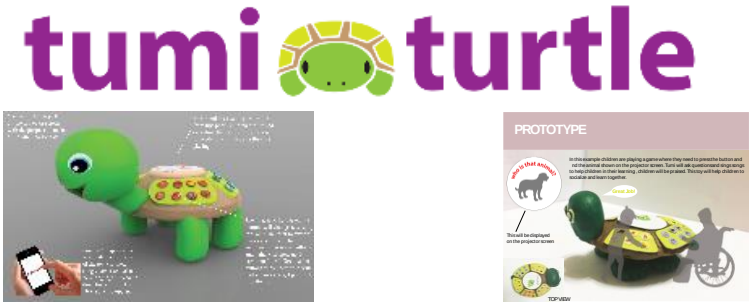

Figure 3. Tumi Turtle is a multi-purpose game table.

4.3 Student Project 3: Tree Haus

Tree Haus (Fig. 4) is a pre-school classroom designed to incorporate sensory spaces and break away areas for all children to work in large or small groups based on their sensory needs and tolerances.

Figure 4. Tree Haus inclusive classroom.

5 Connectivity Model Analysis

The information collected in the Connectivity Model assesses social, emotional, physical, motivational and behavioral data. In the following paragraphs we will analyse and evaluate the model by focusing on student project 1: Perry the Penguin. This project acts as an example that represents characteristics of all three projects:

In a self-assessment of Perry the Penguin using the Connectivity Model data, the student identified several social goals achieved by the design. The game can be played solo or with friends or family. It promotes positive social behaviors through sharing, waiting, and turn taking. It allows the child to help reset the pins for another player or for themselves. It creates a learning experience by matching numbers, shapes and colors of birds to mat. It provides opportunities for organizing the penguins off the ice rink matt in different patterns, understanding and following directions given by game play cards or parents.

Emotional goals were also identified. When playing the game, everyone can celebrate when one player knocks over pins as an emotional reinforcement. If the game is played with a sibling or friend, it creates a friendly competition and encourages collaboration.

Physically, the game involves hand-eye coordination and the fine motor skills required to hold the ball correctly and to stand the pins up. It uses language and verbal prompting to knock over a certain pin. It incorporates hand-eye coordination and mimicking movements to succeed. A variety of textures help kids learn tactile matching.

Behaviorally it requires turn taking, knocking down the pins indicated on the card, and repetitive movements with each successive turn. Pins can be gently tossed back and forth or set up in a specific pattern as indicated by the playing cards. By watching other people take their turns, children can learn the game play.

Winning the game and hearing positive feedback sounds when the birds fall over or when you place them on the correct color or number is motivational.

It is socially motivating and promotes learning through interacting with peers in a fun, safe, and entertaining environment. The textures and colors on the penguin characters are both tactilely and visually stimulating.

This game can be played solo or collaboratively with peers. The game is not branded as a “disability” game. The different colors, textures, shapes, and positive sound reinforcements are learning aids for any child within the 3-4 year old range. Overall it does not stand out as a product created for kids with disabilities, but as a fun game that anyone can play and learn.

6 Discussion

Students were introduced to data-driven, user participatory research for inclusive design through a series of lectures, a YouTube channel with videos, and class discussions on data driven processes. The IRB test was a useful introduction to the ethics and strategies for social and behavioral research. By allowing students to write and address questions to parents they were able to glean useful qualitative data to inform their designs. Access to the YouTube videos gave students a much clearer understand-

ing of the exact behavioral and communication issues in autism than can be understood by only reading about the condition. The combination of lectures, videos and person interviews provided a well-balanced and informative set of data for the Play•IT project.

The lack of face-to-face engagement between student designers and autistic children is a limitation of the approach, whilst also being its defining strength. By definition, participatory design ought to include face-to-face interactions. The application of video observations provides an alternative way for designers to develop empathy for users. Information gathered from parents complemented the video observations, with parents taking on the roles of both proxies and experts.

The Connectivity Model UX research tools effectively helped students identify the social, emotional, behavioral, physical and motivational needs of target audiences both with autism and those who are neurologically typical. Lectures on the Connectivity Model combined with the worksheets appeared to provide a clear method for conducting ethnographic observations. Students were introduced to each aspect of the model and shown examples of what that specifically looks like in a natural setting. By using carefully selected videos, students were able to play the videos multiple times in order to take notes on both the frequency and context of social, emotional, physical and behavioral actions demonstrated by the people in the videos.

The UXD strategies used in the Play•IT project were considered to be successful in this pilot study. All students were able to conduct the UXD research and apply it to their designs. It was used in initial design stages to inform the concept of the project. At later design stages, the video observations and parent interview data was useful in making specific refinements to the designs. By recording these answers in a meaningful way during the parent interview and during the video observations, students were able to find and retrieve the answers that they needed to make decisions about the experience design.

Additionally, this method can be easily implemented in both online and traditional university classes. It does not require lengthy IRB approvals and will allow students to experience what it is like to do actual site observations. By allowing the students to practice developing and asking survey questions, they had the opportunity to gain valuable UXD skills in qualitative research and focus group administration.

7 Future Research

Future research will examine whether an increased awareness of user participatory design strategies produces UX design solutions with a greater connection to the needs of target audiences both with autism and those who are neurologically typical. The Play•IT project will be replicated in other design programs and with different project parameters to test the effectiveness of the UXD methods outlined by the Connectivity Model and the use of online and digital resources. We also hope to be able to expand the scope to include other cognitive and physical disabilities.

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